

National priorities for dementia care : perspectives of individuals living with dementia and their care partners

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Table 3: Federal Government Priorities

	Borda Count	Rank Order
Overall Priorities		
Prioritize caregiver support – financial compensation for caregivers, respite, case management, counseling	644	1
Prioritize long-term care needs (care provided in-home, community, and institutional settings; workforce issues, regulations, and long-term care facilities)	648	2
Prioritize research involving medical factors, social factors, technological approaches to care, alternative approaches to care	722	3
Prioritize education and training for formal and informal caregivers, families, community, staff, workforce	744	4
Prioritize advocacy and awareness about dementia – public education campaigns, aging in place, adequate funding	1057	5
Education and Training		
Skills training for care partners / caregivers / families – e.g. communication, care, utilizing a person-centered approach	588	1
Skills training for workforce (healthcare workers: nursing home and hospital staff, public agency workers, home care workers)	643	2
Provide training incentives to increase the number of individuals skilled in working with persons with dementia (e.g. physicians, nurses, social workers, occupational and physical therapists, counselors)	766	3
Long-term care planning and assistance – understanding, planning and paying for long-term care	881	4
Education on alternative, non-drug approaches for caring for persons with dementia (music & art therapy, massage, touch, person-centered care)	973	5
Caregiver Support		
Financial assistance or funding for in-home and out of home respite	620	1
Financial assistance or funding for in-home support – case management, medical supplies, home care	676	2
Counseling and emotional assistance for individuals caring for the person with dementia – e.g. stress management, how to prevent caregiver burnout, consultation	809	3
Financial assistance or funding for adult day care	854	4
Compensation for individuals caring for persons with dementia	865	5
Long-term Care		
Home and community based services (transportation, affordable assisted living, home delivered meals, care management, resources to support aging in place)	525	1
Building an experienced workforce skilled in provided in-home and nursing home care	702	2
Increasing standards for assisted living facilities, skilled nursing facilities, and hospitals – e.g. oversight of care, avoiding the use of anti-psychotic medications to deal with difficult behaviors, tracking progress and change	741	3
Increasing the number of long-term care facilities skilled in providing care to persons with dementia	858	4
Increasing the number of staff within long-term care facilities – nursing, social work, health care aids	917	5
Advocacy and Awareness		
Support policies that provide adequate funding to support persons living with dementia and their care providers	574	1
Support policies that promote aging in place for the person living with dementia	712	2
Public awareness of resources and supportive services to assist persons living with dementia and their care providers	725	3
Make dementia the number one priority for public health policy	835	4
Public education and help to understand dementia (de-stigmatize and facilitate understanding of the disease)	865	5

Table 4: Research Priorities

	Borda Count	Rank Order
Overall Priorities		
Research about cure and treatment (drug treatment)	689	1
Research about care giving – person-centered approaches, family caregivers and workforce	737	2
Research about education and training – for the person with dementia, families, workforce and the public	848	3
Research about quality of life – the impact of dementia on the whole family	866	4
Research about complementary therapies – supplements, remedies, alternative treatments	936	5
Research about care settings – home, long-term care, day care, hospital	963	6
Caregiving		
How to reduce stress, fear and distress for the person with dementia, the family and all caregivers	732	1
Effective approaches to delivering care and providing support	774	2
Interacting and communicating with the person with dementia	809	3
Managing difficult behaviors without drugs	809	3
Care planning for families – including end of life and financial issues	911	5
Involving the person with dementia in decision making	1046	6
Care Setting		
Providing and supporting care in the home (day care, respite, home help, nursing and medical care)	544	1
Creating a helpful environment for the person with dementia (routines, space, signage, homelike)	703	2
Workforce issues in long-term care and hospital	784	3
Impact of facilities like Green Houses, dementia villages, households compared with traditional nursing homes	809	4
Technology to maintain safety and independence	826	5
Complementary and Alternative Therapies		
Impact of sensory therapies such as music, art, aromatherapy on the person with dementia	517	1
Role of nutrition, supplements in the prevention and treatment of dementia	540	2
Developing methods to measure the impact of complementary and alternative therapies	558	3
Impact of touch therapies such as Reiki, massage, acupuncture on the person with dementia	798	4
Education		
Best practices for educating/training the workforce (doctors, nurses, social workers, lawyers, aids, students etc.)	453	1
Organizational culture change and person-centered approaches to care	486	2
Best practices for educating the person with dementia, family and friends – content, method (classroom, web-based)	529	3
Quality of Life		
How to help the person with dementia remain engaged with life	509	1
How to maintain abilities – physical, cognitive, personal skills and strengths (work issues)	551	2
How to help friends, family, caregivers engage with the person with dementia	716	3
How to measure quality of life and the impact of dementia for the person with dementia and family	753	4